PADRECC Activities

	Houston PADRECC
10/25/02	PADRECC Patient/Family Conference
11/21/02	Speech Therapy Treatment Techniques for PD
	Philadelphia PADRECC
10/02	Grand opening of new PADRECC clinic
11/22/02	Symposium: Treatment of Psychosis & Parkinson's
	Portland/Seattle PADRECC
9/6/02	Parkinson's Disease Update
9/22/02	Symposium: Options and Opportunities
	Richmond PADRECC
11/02	Seminar series for allied health staff begins
5/03	Spring PD Symposium for Patients and Families
	Southwest PADRECC (West Los Angeles)
9/10/02	1st Annual VA/UCLA Research Conference on Parkinson's Disease and Movement Disorders
9/11/02	Research & Treatment for Dementia
NOTES:	**Philadelphia** PADRECC to edit a handbook for NPF entitled "PD: Mind, Mood, and Memory"
	Houston PADRECC has submitted a grant proposal to study PD in Vietnam veterans
	Richmond PADRECC to develop video series on surgical treatment and management of PD

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VA PADRECC CONNECTIONS

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The PADRECCS: A National VHA Consortium

by John Booss, MD, National Director of Neurology, VHA

On February 7, 2001 at the Cannon Office Building of the House of Representatives, the then newly appointed Secretary for Veterans Affairs, Anthony Principi, announced the establishment of six VHA Centers of Excellence in Parkinson's Disease. They are located at Philadelphia, Richmond, Houston, West Los Angeles, San Francisco, and a combined center at Portland and Seattle. The Centers were selected based on merit. They are termed the Parkinson's Disease Research, Education and Clinical Centers, the PADRECCs.

From the start, it was envisioned that the selected Centers would function as part of a nationwide VHA Consortium. It was in fact a precondition of making application. It was also a precondition of making application to participate in the Cooperative Studies Program investigation on deep brain stimulation for the treatment of advanced Parkinson's disease (CSP-468). This landmark study should distinguish which anatomic site in the brain provides the best symptomatic relief.

The PADRECCs are intended to serve all veterans with Parkinson's disease enrolled in VHA. Hence, the consortium has been organized into recommended service areas for which each Center has its own "sphere of responsibility." Each Center serves as a diagnostic and therapeutic referral center, provide education to patients and families, and encourage participation into research activities by providers and facilities within their designated sphere of responsibility. It is hoped that collaborative relationships with interested providers, educators, and investigators will form within each designated service area.

Workgroups have been established across the Centers to knit the PADRECCs together as a cohesive consortium. The Health Services Research Workgroup has taken on the difficult task of accurately identifying the population of veterans in VHA with Parkinson's disease. Another crucial issue is to evaluate the delivery of highly specialized services through a diverse network of locations and providers. The Clinical Coordinators have organized into committees concerning education, public relations, clinical care, and research. Together with the Associate Directors of Education Workgroup, they have taken on vital outreach mechanisms which include informative brochures, the national PADRECC website (www.va.gov/padrecc/), the newsletter, and established a combined subgroup to advance the use of telemedicine. The Associate Directors of Education will work in collaboration with the Employee Education System to develop national level educational programs. A workgroup of the Administrative Officers is planned. Coordination of the PADRECC Collaborative is based at VA Connecticut.

Finally, a word about the Directors. As a group, they are recognized nationally as outstanding leaders in Parkinson's disease care, education, and research. They provide the creative fire and subject matter expertise on which the collaborative is built and which serves veterans so well.

Dr. John Booss, National Director for Neurology, VHA and professor of Neurology and Laboratory Medicine at the Yale University School of Medicine, was chosen by Central Office to oversee the PADRECC Consortium.

visit our website
www.va.gov/padrecc/

VA Health Services Research in Parkinson's Disease

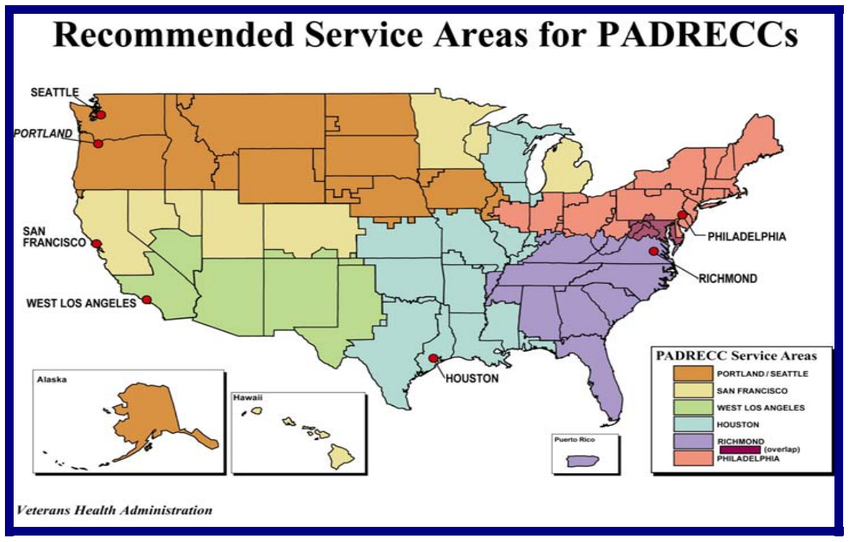
by Barbara G. Vickrey, MD, MPH, Southwest PADRECC

A health services research workgroup that includes four researchers from three of the six PADRECCs has met regularly by teleconference over the past year to collaborate on developing a set of indicators by which to judge the quality of Parkinson's disease (PD) care. When the Department of Veterans Affairs established the PADRECCs in February 2001, one major goal was to improve the care for veterans with this chronic, disabling condition. To demonstrate care improvements, specific ways to measure the quality of care for people with PD are essential. Although a number of guidelines for PD care are emerging from professional organizations like the Movement Disorder Society, we need to develop a set of indicators or "benchmarks" for evaluating the impact of good care across the PADRECCs. These indicators could also be used to measure quality of care in non-PADRECC VA medical centers and in non-VA health care settings.

To date, the workgroup identified and assembled a comprehensive set of existing guidelines and large randomized trials for PD care and distilled these data into a set of about 80 potential PD care indicators. In the next phase of the workgroup's efforts, these indicators and their accompanying evidence will be rated in two rounds by an expert panel consisting of the Directors of the six VA PADRECCs. These ratings will be analyzed to produce a final set of PD care indicators for use by the PADRECCs and others by Spring 2003. They can be used to identify where existing PD care patterns are deficient, to set target goals for improving care, and to measure the impact of putting interventions and programs in place to improve care.

The health services research workgroup is also developing an interview tool to measure unmet health care needs of veterans with PD and is planning to administer interviews with representative samples in the southwestern U.S. next year. This project is supported through a pilot project funded by the VA Health Services Research & Development Service. Members of the workgroup are also analyzing the accuracy of administrative codes for identifying patients with PD from VA inpatient and outpatient databases.

Members of the workgroup are Karleen Swarztrauber, MD, MPH (Portland VA PADRECC); Andrew Siderowf, MD, MPH (Philadelphia VA PADRECC); Eric Cheng, MD, MS (Southwest VA PADRECC); and Barbara G. Vickrey, MD, MPH (Southwest VA PADRECC).



PADRECC map modified from an image provided by the St. Louis Employee Education Resource Center

Clinical Coordinators: Key Members of the PADRECC Team

by Lisette Bunting Perry, RN, MScN, Philadelphia PADRECC

It is with enthusiasm that I introduce you to the Parkinson's Disease Research Education and Clinical Center (PADRECC) Coordinators. This group of dynamic healthcare professionals brings to each PADRECC a diverse background of clinical, academic, and professional experience.

I have had the opportunity to chair the Clinical Coordinator Workgroup. Our first meeting was in November 2001 under the leadership of John Booss, MD, National Director for Neurology, VHA. We identified strategic goals for meeting the needs of PADRECC patients. The workgroup met again in June to review our achievements, plan for next year, and establish committees for clinical research, education, and clinical care. The following are biographical sketches of our PADRECC coordinators.

Pam Willson, PhD, RN, FNP-C, is the Assistant Clinical Director of the **Houston** VAMC PADRECC. She is a board certified family nurse practitioner who has focused on health promotion and prevention as a public health nurse, primary care provider, university professor, and researcher. ***Linda Fincher, RN, BSN*****, Houston** PADRECC Clinical Nurse Coordinator, spent much of her career in nursing administration at the VA. In January 2002 she joined the PADRECC where she coordinates clinical drug trials.

Lisette Bunting Perry, RN, MScN**,** is the Assistant Clinical Director of the **Philadelphia** VAMC PADRECC and a certified clinical research coordinator. She was previously the Nurse Coordinator of the Parkinson's Disease Research Center of Excellence at the Johns Hopkins University School of Medicine. She lectures and writes on PD, quality of life, dementia, and neurodegenerative disease. ***Rebecca Warker, APRN, CS, BC*****,** is the Clinical Nurse Coordinator and Associate Director of Education for the **Philadelphia** PADRECC. Warker, a clinician and researcher with a strong background in psychiatry, has worked with PD patients over the past 4 years. Her special interest is in PD mental health issues, and she is a Psychiatric Mental Health Clinical Nurse Specialist.

Tina D. Conn, RN, BSN**,** Nurse Coordinator for the **Portland** VAMC PADRECC is a former emergency room nurse. Conn spent 18 years in construction prior to earning a nursing degree. Her special areas of interest are movement disorders, education and research. ***Romany Franks, RN, BSN*****, Seattle** PADRECC Coordinator, previously worked in critical care. Her clinical research interest drew her to PADRECC. ***Nanette Eubank, RN, CCRP***, Clinical Coordinator for Hunter Holmes McGuire VAMC and Virginia Commonwealth University Health System in **Richmond**, is a certified clinical research professional with 18 years of experience in neuroscience. ***Mariann Haselman, RN, BS, CNRN*****,** also a Clinical Coordinator at the **Richmond** PADRECC and the Virginia Commonwealth University Health System**,** has coordinated the Movement Disorder Center at the McGuire VAMC for 3 years. ***Peggy Roberge, RN***, a clinical coordinator at the **Richmond** PADRECC, has 10 years of experience coordinating Parkinson's clinical trials. She has also worked as a researcher and administrator.

Susan Heath, RN, MS, is the Assistant Clinical Director of the **San Francisco** VAMC PADRECC. Heath, a neuroscience clinical nurse specialist, helped develop a national surgical program for movement disorder patients. She is an expert deep brain implant programmer and a national speaker on the topic, an educator, a clinician, and researcher. ***Elaine M. Lanier, RN, BA, MS,*** is the Senior Research Nurse for the **San Francisco** PADRECC. She coordinated a nation-wide VA Cooperative Study on epilepsy and functioned as the Admissions Nurse Coordinator for the Epilepsy Unit. Her focus is on clinical research, neurology, and rehabilitation.

Wes Morrow, MS, MMSc, PA-C**,** is one of the Clinical Coordinators for the **West Los Angeles** VAMC PADRECC and the Clinical Coordinator at UCLA for a deep brain stimulation surgery study. Morrow, a physician's assistant with a master's in biological chemistry, has years of experience in basic neuroscience research. ***Alice Cugley, RN, MSN, NP*****,** is the Assistant Clinical Director-Nurse Coordinator of the **Greater LA** Health Care System-WL (GLAHC-WLA) PADRECC. She has 8 years of experience as coordinator of the epilepsy center.

Clinical Coordinators Pam Willson, Rebecca Warker, Lisette Bunting-Perry, and Susan Heath.